



## New Guide to Psychotropic Medications: BY Youth FOR Youth

If you know a young person who takes medications for a mental health condition, you may wish to order the free guidebook, [Making Healthy Choices](#) by the National Resource Center for Youth Development. Although written specifically for foster children, this “toolkit” covers the complex topic of medications in a way that is easy for young people and their parents to understand.



Topics include:

- How Do I Know if I Need Help?
- Symptom Checklist
- What are My Rights?
- What Options Other Than Medication Do I Have?

If you do not have internet access and wish to receive a copy by mail, contact us at 855-323-6744.

### FAST FACT:

59% (an estimated 62,271) of Oregon children with special health care needs do not receive coordinated, ongoing, comprehensive care within a medical home.

Learn more: [www.childhealthdata.org](http://www.childhealthdata.org)



Contact the  
**Oregon Family to Family  
Health Information Center** at  
**1-855-323-6744**

**Stay in touch by joining  
our mailing list!**

## Insurance Updates for Parents of Children with Special Health Needs

2013 will be a year of transition for health care in Oregon. We will do our best to keep families of children with special health needs informed of how these changes will effect you, but in the meantime here are a few updates:

- **Family Health Insurance Assistance Program (FHIAP)** For the time being, FHIAP is still accepting applications for families to receive up to 100% of their child's health insurance premium. This program is ideal for those children whose parents have a health plan through work, but who find it difficult to afford the premium. Call 800-542-3014 for more information.
- **Coordinated Care Organizations (CCOs)** Children who are covered under Healthy Kids are now enrolled in one of 16 local CCOs. (Some children who are medically fragile are not yet enrolled in CCOs at this time.) Each CCO is required to have “Exceptional Needs Care Coordinators” to help families manage the care of children with complex conditions. Members can find out how to access their ENCC by calling the [Client Services Unit](#) at 1-800-273-0557.
- **Coverage for Applied Behavior Analysis (ABA)** Kaiser Permanente is now officially covering Applied Behavior Analysis (ABA) therapy as a treatment for autism and related neurodevelopmental disorders in Oregon and Washington. Kaiser members should contact their customer service representative to determine if their plan is effected by this new coverage.
- **Cover Oregon**, Oregon's Health Care Exchange, will open for business in October 2013. Twenty-five states have started developing a Health Care Exchange as called for in the Affordable Care Act. When it opens, you will be able to easily compare insurance plans and costs. Most Oregonians will be eligible for a **tax credit** to help pay the cost of the premium. Visit [CoverOregon](#) for details.

## Your Child's Medical Home Children with Special Health Care Needs and the Flu



It's influenza (flu) season again so it's time to get vaccinated.

**Who should get vaccinated?** Everyone six months of age and older (including infants born preterm) should get the flu vaccine.

**Why should you and your children get vaccinated?** The flu is a serious illness. It can cause serious complications including pneumonia, hospitalizations and death. Even healthy people can become seriously ill with the flu, but certain individuals, such as children with special health care needs, are particularly at risk for complications. For that reason, the **Centers for Disease Control, the American Academy of Pediatrics**, and other health care organizations **recommend that the following groups get vaccinated:**

- All children and adults with chronic medical conditions such as asthma, diabetes mellitus, immunosuppression, or neurologic disorders;
- All household contacts including children under five years old, care providers of children with high-risk conditions, and those who have contact with babies less than six months old;
- All health care personnel;
- All women who are pregnant, are considering pregnancy, have just delivered, or are breastfeeding during the flu season, and
- People 65 years of age and older.



**It's January. Is it too late to get a vaccine?** No. Talk to your child's pediatrician, school nurse, or your local health clinic or use this [website](#) to find a location near you. **Is your child very afraid of shots?** Ask your doctor about the nasal spray vaccine. **Still undecided?** Read more here: [www.cdc.gov/flu](http://www.cdc.gov/flu), [www.familiesfightingflu.org](http://www.familiesfightingflu.org), or [publichealthoregon.gov](http://publichealthoregon.gov)



## Congratulations! Angel Flight West is the 2012 Oregon Rural Health Hero of the Year



Families in rural communities face additional challenges when their children's health requires travelling long distance for appointments and treatment. In Oregon, we are fortunate to have the services of Angel Flight West (AFW), which was recently named the 2012 Oregon Rural Health Hero of the Year by the Office of Rural Health at Oregon Health & Science University.

AFW is a non-profit, volunteer organization that arranges free, non-emergency air travel to children and adults with serious medical conditions and other serious needs.

If you live in rural Oregon, have a financial need, and your child needs to travel long distances for his or her treatment, you may be eligible for help from AFW. Read more about eligibility requirements in their on-line [informational packet](#) or call them at 1-888-426-2643.



### Alternate Newsletter Formats Available Upon Request



Families of children with special needs who do not have internet access may receive this newsletter by mail by calling **1-855-323-6744**.

## Support Groups Galore

Did you know there are more than 100 support groups for parents, youth, and children with special health needs in the state of Oregon?

As one parent wrote on the "Hopeful Parents" blog, *"No one understands me better than those who share my struggles."* If you agree, maybe joining a support group is for you. Sometimes, however, parents aren't so sure about attending support groups. Some common concerns are:

*"I don't want to sit around and listen to people complain about their problems!"*

Agreed! But you may find that there is less "complaining" and more "problem solving" going on at a support group. Parents are often surprised to see how positive and resourceful the other parents are!

*"My child's condition is so rare, no one will be able to relate to me."* Chances are, there is someone else in the group with unique concerns. Even though the specific condition may be different, our kids are alike in many ways. We share many of the same joys and challenges, regardless of diagnosis.

*"Its too hard to go out, gas is too expensive, and my kids and spouse don't like it when I'm gone."* Going out to a group is not everyone's cup of tea. Luckily, parents can also join support groups on-line or chat with others by phone. Here are a few local and national on-line groups that allow you to connect with others without leaving home:

[Hopeful Parents](#) | [Family Village](#) | [Rare Disorders](#) |  
[Eastern Oregon](#) | [Southern Oregon](#) | [Central Oregon](#) | [Portland Aspergers Net](#)

For information about support groups in your area,  
or suggestions about how to start one, call 1-855-323-6744.

## Help for Parents Navigating the Special Education System

If your child has special health needs, he or she may also receive Special Education Services. In the same way that the Oregon F2F HIC helps families navigate the health system, there are special *Parent Training and Information Centers (PTICs)* in every state that help parents understand their child's special education rights.

Oregon has three PTICs. Call on them when you have questions or concerns about your child's special education. All services are free!



### [Families and Community Together](#)

No matter where you live in Oregon, you can call the IEP Help Line 24 hours a day, seven days a week. Leave a message, and staff will return your call within one business day. **1-888-988-FACT**



### [Native American Parent Information Center](#)

This is a national program based in Grants Pass that provides information (printed, by email, phone and workshops) on disability issues for Native American family members who have children with disabilities. **1-855-720-2910**



### [OrFirst](#)

Provides assistance and training to families in the Portland Public School neighborhoods to understand rights and responsibilities for IEPs and IFSPs. **503-232-0302**

The resources on this page are not comprehensive nor does inclusion imply endorsement by the Oregon F2F HIC or the Oregon Health & Science University (OHSU). These resources are intended to be a starting point for further research. The Oregon F2F HIC is a family-led effort, funded by a grant from the Health Resources and Services Administration/Maternal and Child Health Bureau. The F2F is closely affiliated with the Oregon Center for Children and Youth with Special Health Needs (OCCYSHN), located at the Child Development and Rehabilitation Center at OHSU.